

Take your research to the next level:

10 things to know about creating and using linked health datasets



Creating a linked national dataset from national clinical audits, registries, and other NHS data can be a powerful tool to identify improvements in care. Here are some key things researchers should know to smooth their way.



Designing your study

- 1** Design clear and precise research questions that minimise the impact on patient privacy. Avoid vague ‘exploration of data’ applications.
- 2** Gather as much information as possible about the coverage, data fields and quality of the datasets, early on – including feasibility of data linkage.

Requesting data

- 3** Allocate enough project time for exploratory analysis and build flexibility into study objectives. Research must justify why linked data are required.
- 4** Identify the many approvals that will be needed such as ethics, legal provisions, and data access. The most common pitfall is applicants underestimating the work involved and not clearly setting out all the required information for each application.



Planning your resources and team

- 5 Be prepared for initial estimates of data access costs to change.
- 6 Ensure project timelines allow sufficient time to set up studies, apply for and receive data – this can take a long time and often more than a year.
- 7 Think about the skill mix needed in research teams, especially: data expertise (how data is processed), clinical expertise (how data is entered and interpreted), coding expertise (manipulating the data), and a research coordinator.
- 8 Talk early and often to funders, especially if costs and timelines change. Keep funders informed of progress, learning and challenges.

For further information:
[health.org.uk/insight-2017](https://www.health.org.uk/insight-2017)



Making sense of the datasets

- 9 Build a strong wider network with audit and clinical and commissioning communities, clinical researchers, dataset experts, clinicians, patients and the public. This is crucial to making sense of datasets and doing excellent research.




After completing your study

- 10 Plan for the end of the study from the outset. Think early about whether data is needed after completion (the default is that all data is deleted), consider associated fees and legal requirements, and talk to data controllers about how retention might be achieved.

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